



More Positive Living



STRENGTHENING THE HEALTH SECTOR RESPONSE TO YOUNG PEOPLE LIVING WITH HIV



Over 5 million young people are living with HIV



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2.5 million of them are young women in sub-Saharan Africa

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Preface

An estimated 5.4 million young people 15 to 24 years old are living with HIV (Table 1). There are no good estimates for 10–14 year olds, but their numbers are likely to increase as more and more children infected with HIV have access to life-prolonging antiretroviral therapy (ART). At the same time, for young people who become infected during adolescence, efforts to make HIV testing more available are likely to increase the numbers who know they are infected.

The health sector needs to be clear about its role in addressing the needs of young people living with HIV (YPLHIV). Young people have different needs from children and adults, and require different approaches to meeting these needs (Box 1). They will also have different needs from each other depending on their age and sex, and how they became infected.

To increase understanding, identify gaps and obstacles and make practical recommendations to improve the role of the health sector in the provision of care, support, treatment and prevention for YPLHIV, WHO & UNICEF convened a global consultation in Malawi, 13 to 17 Nov. 2006. There were more than 45 participants from 18 countries at the meeting, including health workers, young people living with HIV, and representatives from UN agencies and nongovernmental organizations

(NGOs) that work with YPLHIV or support programmes designed to meet their needs.

The young people and the health care providers present at the consultation reached good consensus on how to strengthen the health sector response to YPLHIV.

To start the consultation, young people presented “maps” based on their own or other young people’s experiences from infection through to diagnosis, care and treatment. These vignettes helped to focus the discussions on real people, in real situations with real problems. Two background papers had also been prepared for discussion during the meeting, one representing the voices of young people and the other the perspectives of health service providers. These papers and the report of the meeting, *WHO/UNICEF global consultation on strengthening the health sector response to care, support, treatment and prevention for young people living with HIV*, can be found on the Internet.¹

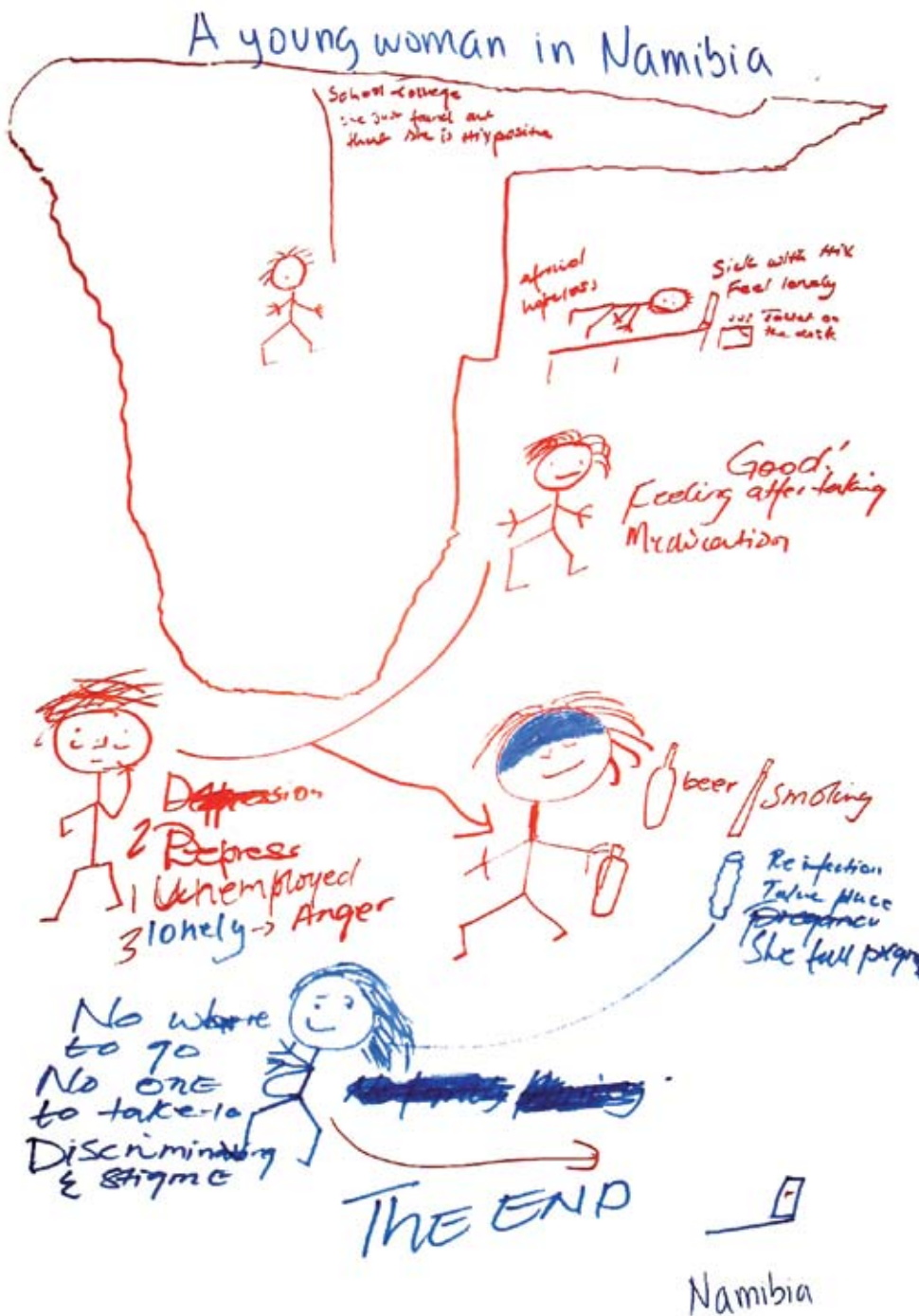
“Please listen to the voices of positive youth...”

¹ WHO/ UNICEF, 2008a; 2008b; 2008c. For the source of the quotes in this publication, which are authentic voices of YPLHIV, see WHO, 2008b.

Table 1
Young people (15-24) living with HIV/AIDS

	Female	Male	Total
Sub-Saharan Africa	2 500 000	780 000	3 200 000
South Asia	270 000	440 000	710 000
East Asia and Pacific	110 000	450 000	570 000
Latin America and Caribbean	140 000	280 000	420 000
Eastern Europe (CEE/CIS)	100 000	240 000	340 000
North Africa and Middle East (incl. Sudan)	47 000	35 000	81 000
Totals (non-industrialized countries)	3 100 000	2 200 000	5 400 000

Source: UNAIDS/WHO, *AIDS Epidemic Update*, 2007



A YOUNG WOMAN IN NAMIBIA

This map illustrates the importance of ongoing counselling to prevent self-destructive behaviour. "She is still at school when she finds out that she is HIV positive. She falls ill and feels lonely. After getting the medication she feels better, but her anger and loneliness do not go away, so in order to fight this feeling she drinks alcohol, smokes and practices unsafe sex until she gets pregnant."

Box 1

How are young people different?

There are many ways in which young people are different from small children and adults. This affects their needs and how the health system should respond.

Adolescents often have a sense of immortality and find it difficult to think about future consequences of today's actions. With an emerging sense of autonomy they challenge authority, and it is normal during this phase of development for them to seek new experiences, some involving risks. This has implications for the information and support that they

require, and how they respond to the advice provided by health workers.

Young people are vulnerable to peer pressure and to concerns about body image. They have less structured lives than adults, which may make treatment adherence more difficult. Unemployment and poverty are important issues for many young people, and they often rely on their parents financially, and in other ways. These factors limit their ability to make independent decisions about using health and other services.

Challenges demanding response...

The international community has committed itself to providing care, support, treatment and prevention for young people living with HIV. In some countries HIV prevalence is decreasing among young people due to prevention efforts and reduction in risk behaviours (Box 2). There are also signs that the scaling up of ART access is reducing HIV-associated deaths and prolonging people's lives in many countries.

But despite these successes in prevention and treatment, there are still shortcomings in the health sector response to young people. For one thing, as ART reaches more and more HIV-infected children, they will require special attention as they progress through adolescence into adulthood. Even in countries where the standards of living are high and ART available and affordable, the care and support elements need more attention. Although the body is taken care of, the psychosocial and emotional needs often remain unmet.

There are positive examples of support and care to YPLHIV, which should inspire and show the way. But the general picture is far from comforting. From pockets of relative well-being for YPLHIV in some countries the panorama stretches to young HIV-positive men and women in states of isolation, fear, anger, illness and poverty, without any support. Many are orphans and homeless.

Those who have been tested and know their HIV status are just the tip of the iceberg. Over 4.3 million young people worldwide have no knowledge that they are infected with HIV.¹ They behave like other young people, often taking risks. Testing, hand-in-hand with counselling and support, can be a start to guide them into healthy positive living, to protect themselves and others. Testing without support can start a negative cycle of behaviour that harms the young person living with HIV – and others.

¹ Over 80% of YPLHIV have never been tested. Some estimates give 86% (WHO/UNICEF, 2008a)

Even young people who know their status find it difficult to access health services, or may avoid them, with obvious implications for further transmission, and for care, support and treatment. The majority of YPLHIV receiving treatment have been vertically/perinatally infected (as in Botswana and Uganda, for example). Although many of those who became infected during adolescence are unlikely to require treatment until later in life, they all need care and support now.

“Why do they treat people with HIV suddenly so differently? When will they learn that HIV is about much more than just learning the facts?” – Daniel, United Kingdom

“Young people are very scared and confused especially when they have no-one to turn to.” – Amelia, Namibia

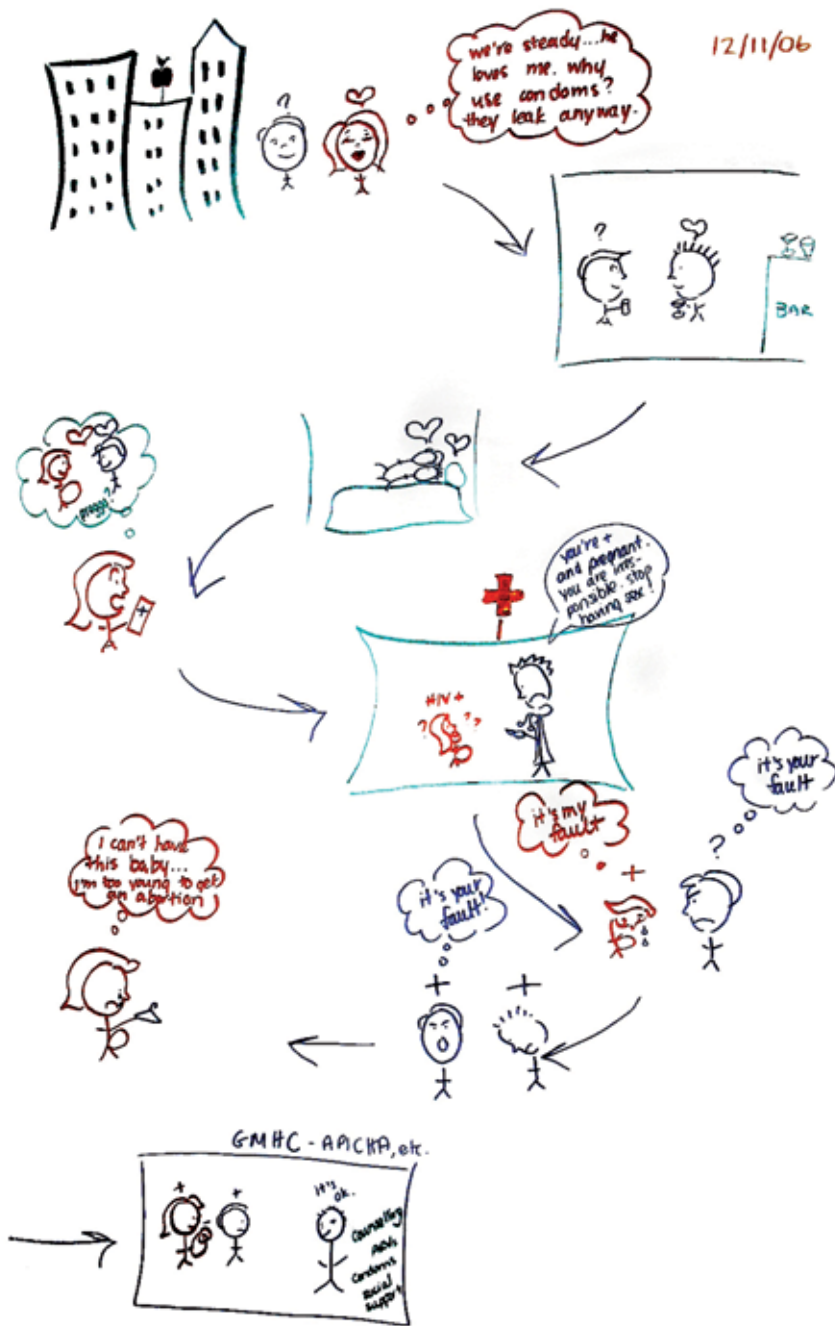
Box 2 Some victories in the response to HIV among young people

In Botswana, prevalence among women aged 15-19 years decreased from 25% to 18% between 2001 and 2006, and among 20 to 24 year olds it declined from 39% to 29%. In Zambia, prevalence dropped from 30% in 1994 to 24% in 2004 among 20-24 year olds.

Analysis of data from sentinel surveillance systems shows that in 11 of 15 most-affected countries, prevalence among pregnant women 15-25 is declining, with significant decline of more than 25% observed in Kenya (urban and rural), Côte d'Ivoire, Malawi and Zimbabwe (urban), and Botswana (rural).

An important reason for the declines in new infections in Kenya and Zimbabwe is a reduction in risk behaviours among young people.

Source: UNAIDS/WHO, 2007.



A YOUNG WOMAN IN NEW YORK

The map shows how support can work wonders. It tells the story of a young girl who is alone when she finds out about her pregnancy and HIV positive status. Everywhere she is met with accusation: "It is your fault". Fortunately she finds GMHC (Gay Men's Health Crisis) and APICHA (an NGO in New York that serves Asian migrants) and a good counsellor who is able to explain the facts about her pregnancy and her HIV positive status, with the happy ending of having an HIV-negative baby.

INDIA (below):

Young women attend an information session on Prevention of Parent-to-Child Transmission (PPTCT) at the V.V. hospital in Bangalore. UNICEF is working with the Government and other partners to develop expanded educational programmes that offer PPTCT counselling in government hospitals. © UNICEF/ HQ04-1214/ Ami Vitale



Barriers to access – unmet needs

There are many different barriers that limit young people's access to and use of health services: organizational, economic, social, and often simply a lack of trust. The first step in knocking down the barriers is to listen to the voices of young people...

The experiences shared at the meeting by young people living with HIV illustrated why many young people avoid contact with the health system for testing, care and treatment. They feel that their needs are not being met.

Trust and understanding

Although there have been improvements in the ways that health workers approach YPLHIV, health services still have a long way to go to win the trust of young people.

As illustrated by young people who answered a questionnaire sent out before the Malawi meeting, lack of respect for privacy and forced disclosures after testing are major concerns. Fear of disclosure may be a very strong deterrent to young people making contact with health services, as unplanned disclosures could have serious consequences for their relationships and employment opportunities.

Stigma and discrimination also tarnish young people's experiences of the health services, from the first visit and onwards into care and treatment. In particular, young people infected through their own sexual activity often find that health workers are judgemental, and may deal out large doses of blame. Concern about being judged is thus another obstacle to continued use of health services.

Adolescent/youth-friendly approach

On the whole, health services are child and adult oriented, and have not been designed to meet the special needs of young people. In general, there is a lack of expertise in dealing with adolescents and their problems. In particular, there is a lack

“In my case, my whole college knew about my test – the health center revealed my status.” – Julio, Bolivia

**“A nurse did not want to take my blood, nor be in a room with me because I was HIV positive. I was turned away from the clinic because of my HIV status.”
– Marco, Canada**

“In the hospital where I go to see my doctor, he puts yellow stickers on all my blood sample requests.... Surely, they ought to be treating all of us who they take blood from the same, to protect themselves instead of labelling just some of us as dangerous and others not?” – Daniel, United Kingdom

of understanding about the mindsets of young people living with HIV, including their desire to fulfil sexual and reproductive needs.

Sexual initiation is a normal part of adolescent development. Furthermore, for young people living with HIV, intimacy and having children of their own can seem like the only ways to survive, emotionally and genetically. But YPLHIV are seldom provided with information, support and understanding for their emerging sexuality, their sexual orientation, or their reproductive choices; and they are too afraid to discuss these issues with health workers because of concerns about confidentiality or judgemental attitudes.

There is a lack of accurate and understandable information on issues relating to healthy life choices, targeted explicitly at young people.



Psychosocial support

A vital need brought up over and over again by young people and their health providers was psychosocial support. Stigma and discrimination in society meet YPLHIV at every turn. This can force them into complete isolation or, at best, force them to build double lives: a life within the community, school and workplace, where they hide their HIV status, and another life with peer groups, counsellors and other people who know their secret.

Psychosocial support is important to bridge the isolation and to help young people find strategies to counter stigma, to cope with fear and hopelessness after diagnosis, and deal with issues such as disclosure to partners, friends and family.

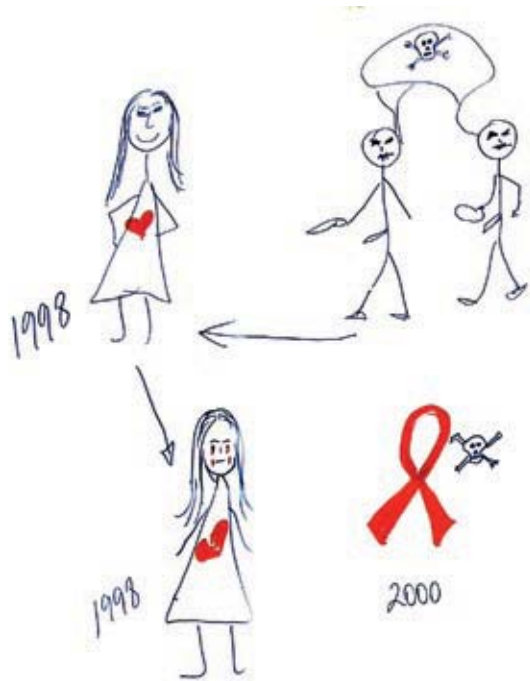
Without the psychosocial support of peer groups or trained professionals, many young people are marginalized and fall back on drug-taking, alcohol and risky sex as solutions for distress.

Support is essential before and during treatment. Young people often have difficulties with

“Really the time to wait [for test results] produces desperate anguish.... At the end when I got the results, it was important to speak with a peer counsellor and meet someone who had the virus and looked healthy.” – Fernando, Peru

**“Living a double life was never something I thought of.... Now [thanks to the Teen Spirit support group] I have friends that understand what it feels like to be me.”
– From Body & Soul Newsletter *Hope***

ZIMBABWE (above): Members of the youth group Young People We Care (YPWC) sit together in a circle during a meeting at the secondary school in Madziire Village in the eastern Manicaland Province. YPWC is a UNICEF-assisted counselling and peer support group for children affected by HIV/AIDS. © UNICEF/ HQ06-0411/Giacomo Pirozzi



A YOUNG WOMAN IN BOLIVIA

The desires of a young woman for love and family illustrated in this map turn to despair after she is raped and diagnosed with HIV. Thanks to support and care her hopes and dreams return.



A young woman in Bolivia

adherence “linked not only to the side-effects but also to the acceptance of the HIV infection, self-esteem and discrimination”.¹ Adherence is also jeopardized by general lack of structure in their lives. There is a lack of personnel with training for the task of building a *therapeutic alliance* that involves helping the patient to deal with everyday problems, creating readiness for treatment and then providing ongoing support.

Other needs

Health services should be accessible and affordable. YPLHIV may not be able to pay for the services that they require, as so many of them are affected by unemployment and poverty (Box 3). Structural/organizational difficulties also create barriers. For example, different elements of a comprehensive health sector response to YPLHIV may be provided through different health workers in different facilities that are geographically separated. The dream is a one-stop-shop devoted to care, support, prevention and treatment for young people, but of course this has a price tag for the health system. A minimum for sexually active young people is condom provision and treatment for sexually transmitted infections.

It is important to ensure that adequate effort is directed to supporting young people as they transition from paediatric to adolescent care, and subsequently from adolescent to adult care. This is particularly challenging in resource-poor settings.

In addition to the problems of referral within the health sector, there is the challenge of referral from health services to other sectors, such as social services and education/training.



SUDAN:
A boy watches his team play football on an airstrip in the town of Nyal. © UNICEF/ HQ05-2093/Georgina Cranston

¹ Elizabeth Franco quoted in WHO/UNICEF 2008b

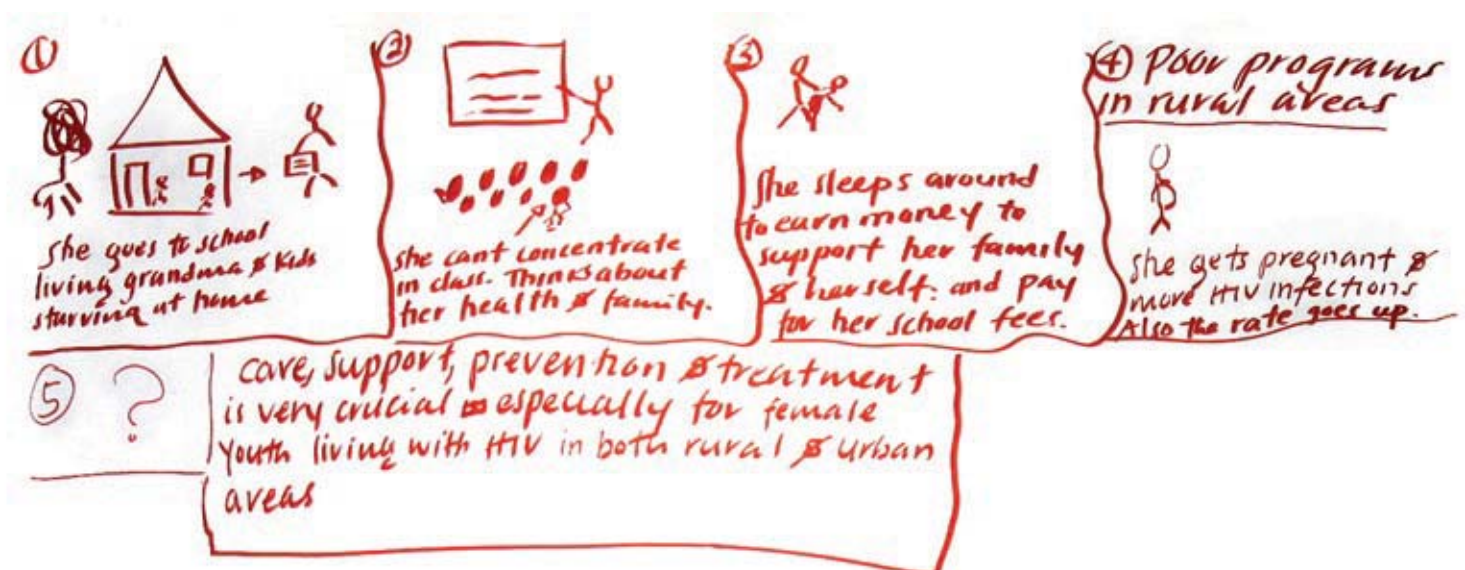
Strengthening the health sector response

Young people and health providers came to a clear consensus. In order to increase uptake, health services need to be available, accessible and appropriate to adolescents, responding to their needs and their rights, and taking into consideration age and gender differences. Health workers and other clinic staff must be trained to develop the necessary orientation and skills. Young people living with HIV need to be involved in the provision of information, support and other interventions delivered through health facilities, since a young person who is newly diagnosed with HIV is likely to identify best with another person who is living with HIV.

To generate demand and strengthen community support for adolescent-friendly health services, young people, parents and community members need to be informed about their availability. Every attempt should be made to ensure that health services for YPLHIV are integrated into the overall response of the health sector to providing treatment, care, support and prevention to people living with HIV, particularly in resource poor settings.

It was agreed that YPLHIV require:

- developmentally appropriate information on anatomy and physiology, HIV transmission, disease progression, treatment literacy, risk reduction and positive prevention;
- HIV care and treatment, the prophylaxis and treatment of opportunistic infections, ARVs, and adequate nutrition/food;
- mental health and psychological services to respond to adjustment issues, guilt, anger and depression;
- respectful sexual and reproductive health services (including a focus on sexuality, sexual orientation, fertility, abstinence, condoms, contraception, emergency contraception, sexually transmitted infections, medical termination of pregnancy, and antenatal and delivery care);
- linkages and referral between services (including linkages between HIV testing services and treatment, care and prevention).



A young woman in Tanzania

Priorities for wider action

Health providers and young people agreed on a set of priorities for action by the health sector to broaden the response to young people living with HIV. Partnerships should be strengthened between private and public sectors and with community-based organizations. Families and communities should be considered important partners for meeting the needs of YPLHIV, while young people should be key actors, particularly young people living with HIV. There is a need for interventions that respond to the vulnerability of young people (Box 3), and the health sector has an important role in advocating for such interventions.

Lessons learned

What makes health sector programmes for YPLHIV successful? Factors identified by health providers at the Malawi consultation are presented in Table 2.

Table 2
Factors that facilitate or prevent success

What makes health sector programmes for young people successful?	What prevents health sector programmes for young people from being successful?
Youth specific information and resources	Lack of specific attention to YPLHIV
Appropriate and sufficient personnel	Inadequately trained health workers Stigma and discrimination by clinic staff
Adequate resources to make services available and accessible	Lack of consistent resources
Supportive policies and standards	Lack of planning and standards
“One-stop” services	Lack of linkages and referral Lack of support services
Services responsive to the needs of young people	Inappropriate package of services Inappropriate delivery of services
Involvement of YPLHIV	
Creation of support groups and networks	
Effective monitoring and feedback	



DEMOCRATIC REPUBLIC OF THE CONGO:
A woman health worker performs a rapid HIV test at a local health centre in Likasi. The hospital’s programme for prevention of mother-to-child transmission offers voluntary counselling and testing, as well as anti-retroviral therapy for HIV-positive women and their infants. © UNICEF/ HQ05-2189/Giacomo Pirozzi



HAITI (left):

An adolescent holds a dose of antiretroviral (ARV) medications at La Maison Arc-en-Ciel (Rainbow House) in Port-au-Prince.

The UNICEF-supported orphanage provides food, shelter, medicine, education and psychosocial care for children who are living with or have been orphaned by HIV/AIDS. Since the shelter was established, 55 children have been admitted, 16 have died and three have been returned to their extended families. The shelter currently houses 36 children, of whom 26 are HIV-positive and 17 receive ARV drug therapy. © UNICEF/HQ05-0864/Shehzad Noorani

Box 3

Risk and vulnerability

The risk of HIV infection depends on individual behaviours that increase the chance of becoming infected with HIV, such as unprotected sex, and the individual and societal factors that make it more likely that such behaviours will be adopted – factors that increase vulnerability. Factors that increase young people's vulnerability to becoming infected with HIV are also likely to make it more difficult to respond effectively to the needs for care, support, treatment and prevention for those infected.

In order to decrease risk, it is important to provide young people with the information, life skills and services that they need to avoid high risk behaviours such as unsafe sex and sharing injecting drug equipment. For example, they need to know about the importance of using condoms, to know where to purchase condoms and be able to negotiate their use, and to be able

to obtain condoms and access harm reduction services. The health sector has an important role in decreasing risk.

At the same time it is essential to attend to those factors that increase young people's vulnerability to adopting high-risk behaviours which, at the same time, decrease the likelihood that they will receive the health services that they need if they become infected. These include factors such as poverty, social attitudes such as discrimination and marginalization, migration, unemployment and homelessness, exploitation and abuse. Most of these factors are not directly amenable to health sector interventions. However the health sector has an important role to play through the collection, analysis and dissemination of strategic information, advocacy, and mobilizing and supporting other sectors.

Conclusions & recommendations

Young people and health providers attending the Malawi consultation agreed on the following.

1. Young people's voices should be heard: not just their requests for help but also their advice and knowledge. Many young people are already making a valuable contribution to national HIV/AIDS efforts, and others can do the same, both in planning services and as caregivers.
2. One of the biggest challenges is the attitude of health workers. To make health services adolescent/youth-friendly, more training is needed for service providers. Stigma and discrimination within health services need to be addressed, which requires that all employees be better sensitized to the needs and rights of YPLHIV.
3. Some YPLHIV will be sexually active and some young women living with HIV may want to become pregnant. Care and support programmes should help to ensure that YPLHIV have access to a full range of sexual and reproductive services.
4. It is essential to bear in mind the different needs of YPLHIV, in particular those infected during adolescence and those infected during the perinatal period. The health sector needs to provide YPLHIV with:
 - developmentally appropriate information about HIV and AIDS,
 - affordable physical and psychosocial care and treatment for HIV and AIDS, and
 - linkages and referral between services in the health sector and those supplied by other sectors.
5. Innovative and sustainable ways of attracting YPLHIV and retaining them in the health services are needed. Some key actions that would help to strengthen the health sector response are:

- developing and implementing standards for health services for YPLHIV,
 - providing a minimum treatment/care package for YPLHIV,
 - training and supporting health workers, other clinic staff, and young people, including YPLHIV, to strengthen the provision of effective and appropriate services.
6. The health sector also has an important role to play in ensuring that:
 - data that are collected are disaggregated by age and sex,
 - policies and legislation take into consideration the specific needs of adolescents (age of consent for HIV testing, for example),
 - advocacy for YPLHIV remains strong and effective, both to decrease their vulnerability and to respond to their needs for treatment, care and prevention.

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Further references and bibliography can be found in the above publications. The WHO/UNICEF publications are available on the Internet at http://www.who.int/child_adolescent_health/documents/en/



BRAZIL (above):

Children dance in the playroom at GAPA (Grupo de Apoio à Prevenção à AIDS, or Support Group for the Prevention of AIDS) in Salvador, capital of the eastern state of Bahia. Many of the children are being treated with ARV therapy, provided free of charge by the Ministry of Health. The UNICEF-assisted NGO advocates for the rights of HIV-positive children, including the

right to life, health, nutrition, education, social and community life. GAPA works in both rural and urban settings, reaching across the social, political and racial spectrum. The NGO also provides HIV counselling, and social, material and legal support to people living with HIV/AIDS and their families.

© UNICEF/HQ06-1323/Claudio Versiani

Box 4

Doing what needs to be done

Children and adolescents who were born with HIV often experience anger, frustration, sadness and loss of confidence. Watching parents fall ill or die, instills fear and anxiety about the future. Stigma and discrimination make it impossible for them to speak openly about their status, so they live in silence and isolation.

Body & Soul is a charity in the United Kingdom that supports children, adolescents and their families who are living with or are closely affected by HIV.

The majority of young people who are living with HIV at Body & Soul were infected through mother-to-child transmission. Many of them have endured threatening illness and maintained a strict treatment regimen for a very long time.

Body & Soul holds monthly groups for HIV-positive adolescents and children that focus on a range of

issues: treatment updates, adherence to medication, HIV and the body, controlling anger, managing conflict, keeping healthy, coping with bullying and dealing with loss. For many of the young people, it remains the only place that they can talk openly about HIV with others who are the same age. It offers them a safe space in which they can learn about HIV, share their experiences, their fears and ultimately be there for one another.

“I have been able to talk to other children like me and it has really helped.” – Joshua, 12 years old

“... Before I started coming to the group I used to block everything out. I thought if I did that the HIV would just go away.” – Anna, 12 years old

Source: WHO/UNICEF, 2008b: Adapted from a document prepared by Body&Soul.

Acknowledgements

The text of *More Positive Living* was written by Gill Dwyer, based on a meeting report and background papers from a WHO/UNICEF global consultation on strengthening the health sector response to care, support, treatment and prevention for young people living with HIV. Gracia Violeta Ross captured the authentic voices of young people and Sabrina Bakeera-Kitaka synthesized the experiences of services providers.

The graphic design by Aleah Liane Stanbridge features vignettes created by young people at the meeting.

The photographs supplied by UNICEF depict young people engaged in advocacy, young people affected by HIV (with family members who are ill or who have died from AIDS), and some young people who are themselves living with HIV.

Cover photographs

Front cover:

MALAWI: Esnaro Kunika watches her grandchildren enjoy games and dance. Esnaro provides for 10 of her grandchildren who were orphaned when their parents died of AIDS.

© UNICEF/HQ06-0942/Giacomo Pirozzi

SOUTH AFRICA: Moradi Dlamini, aged 21 years, holds her daughter at the Harriet Shehzi Paediatric AIDS Clinic in the city of Soweto. Both are HIV-positive. © UNICEF/HQ06-1368/Giacomo Pirozzi

Inside front cover:

MALAWI: Sungeni Kapalamula, aged 11 years, lives alone with her sister in unsafe conditions after losing most of their family to AIDS.

© UNICEF/ HQ05-1386/Christine Nesbitt

Back cover:

SUDAN: Hazarhirally Hassan, pointing to a poster on a tree, conducts an informal session for women on the prevention of HIV/AIDS and other sexually transmitted diseases, in the village of El-Greer, near Nyala. She is a counsellor at a UNICEF-supported voluntary counselling and testing centre in Nyala. © UNICEF/ HQ06-0583/Shehzad Noorani

Cover design: Aleah Liane Stanbridge

Printed in India



Over 5 million young people 15 to 24 years old are living with HIV. Despite successes in prevention and treatment, there are shortcomings in the health sector response to young people living with HIV. Why are so many young people unable to access the health services that they need, and why do so many avoid them? What are the gaps and what are the obstacles? At a global consultation, young people and health providers came to a consensus on ways to strengthen the health sector response to meeting the needs of young people living with HIV for care, support, treatment and prevention.

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