



More Positive Living





**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

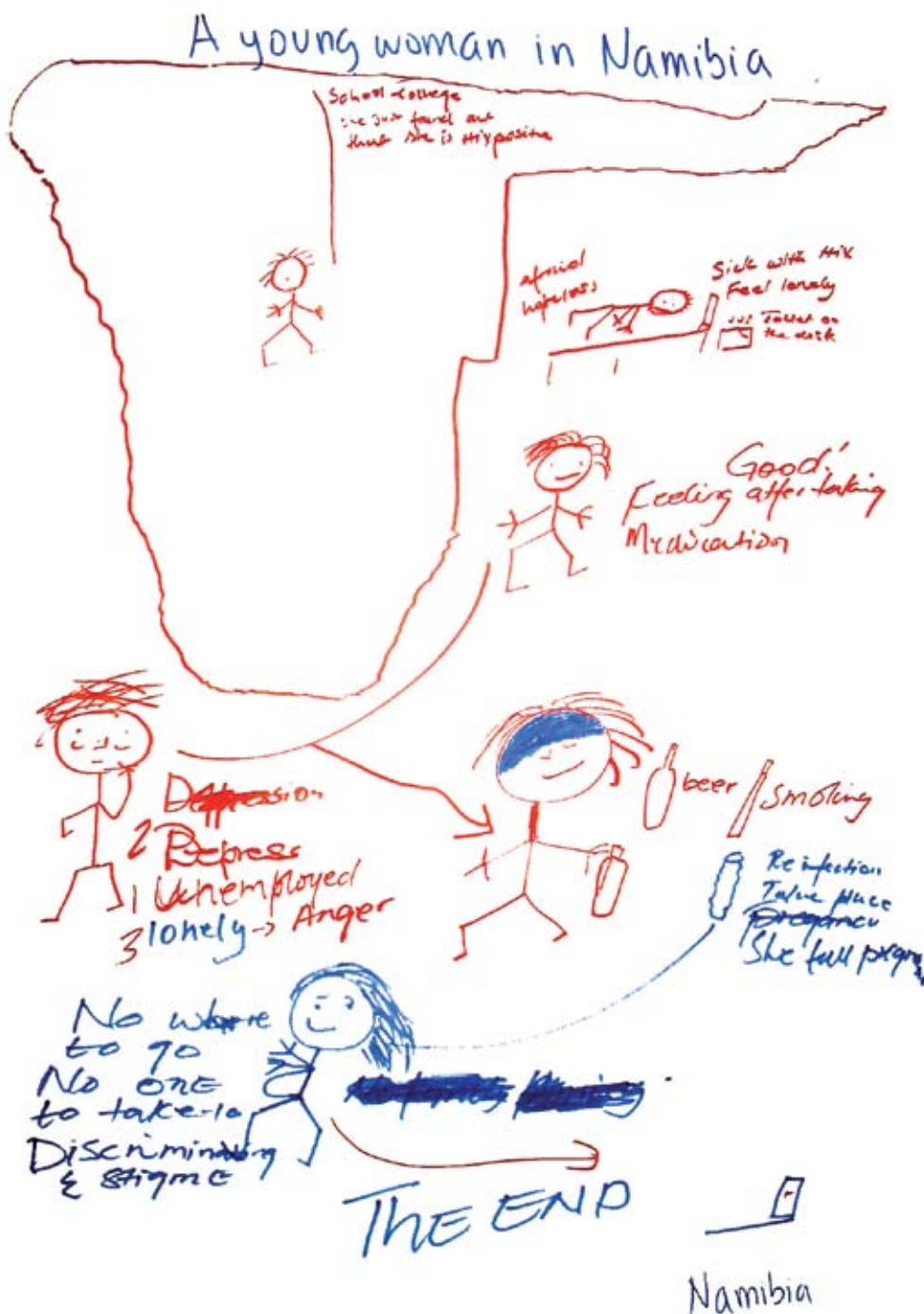
“Please listen to the voices of positive youth...”

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

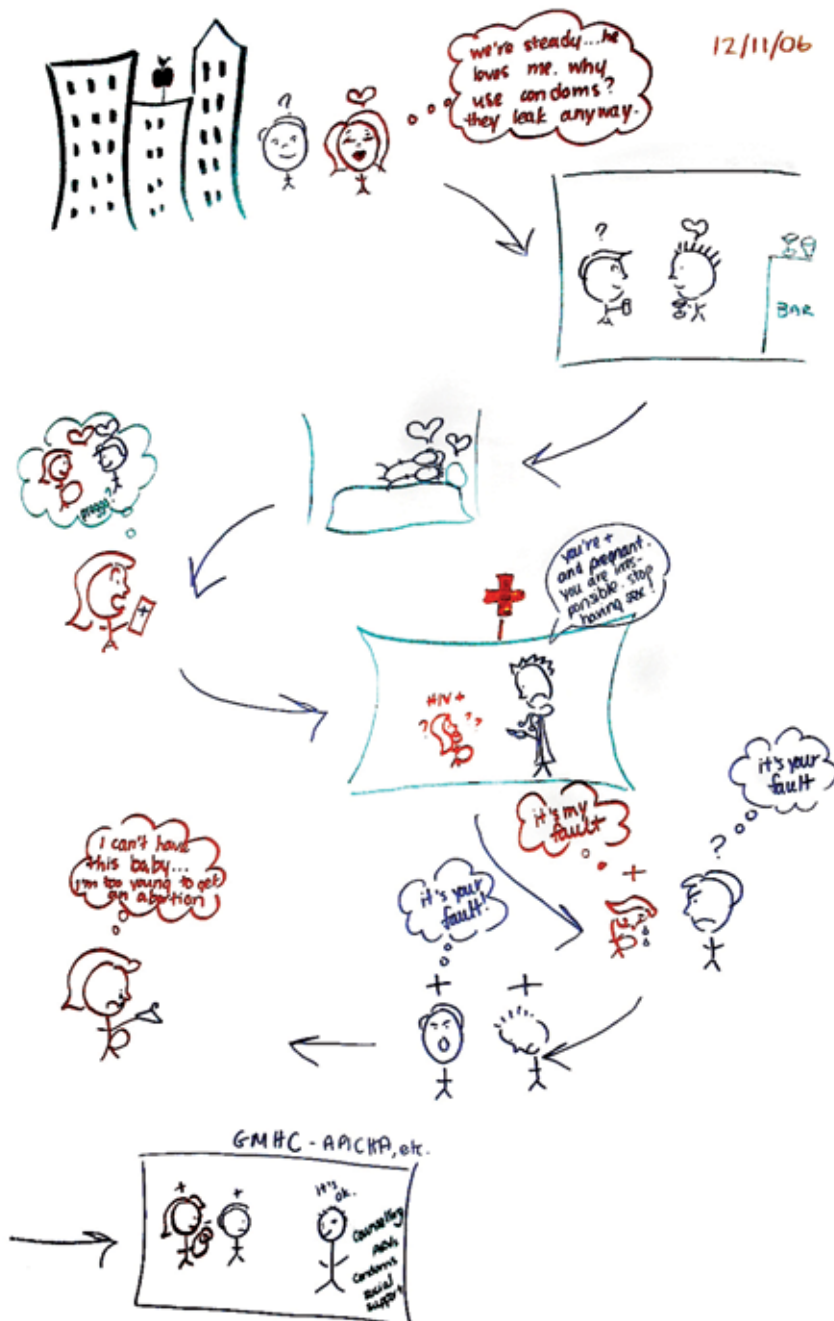
Box 2 **Some victories in the response to HIV among young people**

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.

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]

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